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# Epilepsy Postings on You Tube: Exercising Individuals' and Organizations' Right to Appear

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Title:

Epilepsy Postings on You Tube: Exercising Individuals' and Organizations' Right to Appear

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Title for Running Head: Epilepsy on YouTube as the Right to Appear

**Abstract:** Philosopher Hannah Arendt maintains that everyone has the right to appear in public as an embodied, singular individual. Because of the stigma attached to epilepsy, many with this condition are denied this right. Using grounded theory techniques, the authors analyze uploads of epilepsy on YouTube. The authors argue that personal uploads on YouTube are the only mass media examples in which those with epilepsy can exercise their right to appear without the interpretation of intermediaries. Emerging themes relating to "the right to appear" allow social workers to deepen understanding of this and other devastating, often invisible and sometimes life-threatening illnesses.

**Key words:**

epilepsy, seizures, chronic illness, YouTube, mass media, human rights, video-sharing

## Epilepsy Postings on You Tube: Exercising Individuals' and Organizations' Right to Appear

### Introduction

In her seminal discussion of human rights, Hannah Arendt says that everyone has the right to appear as an embodied, singular individual (Arendt, 1998). Through speech and action, one becomes animate in the public domain, the space where one appears to others as others appear to him or her. Everyone has the right to belong and to participate in the political life of the community; this space guarantees one's humanity. Indeed, "wherever the relevance of speech is at stake, matters become political by definition, for speech is what makes man a political being" (Arendt, 1998, p. 3). The loss of the right to appear causes one to become invisible or to disappear from society. People with epilepsy have been hidden from view or have been encouraged to hide their condition for thousands of years (Engel, Pedley & Aicardi, 2008; Jacoby, 2008). YouTube is the only form of mass media that allows those concerned with epilepsy to appear as they wish in the widest possible public domain, the internet. This research is related to ongoing studies of representations of seizures and epilepsy particularly in broadcast media (film and television) but also in newspapers and popular music (Baxandale, 2003, 2008; Kalra, 2011; Kerson, Kerson & Kerson, , 1999, 2000; Krauss, Gondek, Krumholtz, Paul, & Shen, 2000; Kerson & Kerson, 2007; Kerson & Kerson, 2008; Kerson, 2010; Moeller, Moeller, Rahey & Sadler, 2010). The very nature of broadcast media means the audience shares a common culture that is fixed and passive.

YouTube is the focus of this study because it dominates video sharing. YouTube advertises itself as a global means to Broadcast Yourself through which anyone with a little technical proficiency and standard software can create and upload content on the Internet and disseminate it widely without cost (Jenkins, 2006; Zittrain, 2009). While contributors can range from large

media producers to individuals, most postings are made by amateurs who wish their experiences to be shared directly with a potentially limitless audience (Hand, 2008; Steigler, 2010; Wesch, 2008). Those posting want to hold viewers' attention, create a connection to those who upload their videos, and perhaps develop social networks (Lange, 2010). Postings try to transmit a present-focused sharing of a moment or a certain state of affairs in the uploader's life. These communications often call for a response from the audience (Snickars & Vondereau, 2010). Quantcase.com, a website devoted to measuring or estimating audience, reports that the audience for YouTube is 17.7 million people per day in the United States (Quantcase, 2010). Every minute, 24 hours of video are uploaded (YouTube Fact Sheet, 2010).

YouTube is unique in that it allows users to alter and adapt the site to their own needs (Zittrain, 2008). This is its power and its problem. It makes it possible to move videos to other websites; a piece of html that accompanies each video allows YouTube videos to be embedded in blogs, social networking pages and other internet sites. However, this capacity allows viewers to separate the video from its explanatory material, whether it be written or oral commentary, and material that is taken out of context can have its meaning altered significantly (Strangelove, 2010; Witness, 2010). Thus, posters can lose control of their images and messages.

This issue is meaningful for those with epilepsy and other chronic conditions because they are already faced with loss of control in relation to their lives and bodies. As Frank (1995, p. 30) suggests in his seminal work, *The Wounded Storyteller*,

People define themselves in terms of their body's varying capacity for control. So long as those capacities are predictable, control as an action problem does not require self-conscious monitoring. But disease itself is a loss of predictability, and it causes further losses: incontinence, shortness of breath or memory, tremors and seizures, and all the other "failures" of the sick body. Some ill people adapt to those contingencies easily; others experience a crisis of control. Illness is about learning to live with lost control.

Uploading on YouTube gives people the best opportunity to control what they wish an infinite audience to see and know about themselves. Gilda Radner, who sadly died before video-sharing came into existence, talks a great deal about this kind of control in her autobiography, *It's Always Something*.

Comedy is very controlling – you are making people laugh. It is there in the phrase “*making* people laugh. You feel completely in control when you hear a wave of laughter coming back at you that you have caused. Probably that’s why people in comedy can be so neurotic and have so many problems. Sometimes we talk about it as a need to be loved, but I think with me it was also a need to control. I’ll make the decision whether to come out in my underwear or not, and I’ll make the decision whether you see it or not. It’s like standing in from of a whole group of people and having them under your spell, having them in your power, and not letting them get at you first. The hard part about illness and cancer is that it feels so out of control” (1989, p. 183).

Knowing that these postings can be altered presents another kind of loss of control.

On YouTube, one finds great variations of voice, use, and auspices. “YouTube’s *value* as a cultural archive is a result of its unfiltered, disordered, vernacular, and extremely heterogeneous characteristics” (Burgess & Green, 2009, p. 89), resulting from the loss of institutional control over the representation of events and moving images (Strangelove, 2010). While it continues to provide a means for personal expression, it is also a meta business, “a new category of business that enhances the value of information developed elsewhere and thus benefits the original creators of that information” (Weinberger, 2007, p. 224). Now that YouTube has been bought by Google (Google buys YouTube, 2006) which includes advertising with postings and is forging connections with commercial forms of mass media, such personal postings as those that are the subject of this work may disappear.

A recent study of epilepsy on YouTube concludes that misinformation and stigma persist. To assess videos’ impact on the viewer, Lo, Esser & Gordon (2010) studied the top 10 most viewed videos on YouTube that included content on epilepsy and seizures. They analyzed comments

according to emotional impact and whether the video provided information, was neutral or sought information. They found less information-seeking comments than information-providing ones. The commentators reflected general negative public attitudes.

### Method and Findings

We have collected and analyzed a data set of 127 videos using the words epilepsy and seizure posted on YouTube between July, 2006 and December, 2011. The authors have seen all videos and have perfect agreement about categorization. To code the information, we used grounded theory techniques including simultaneous involvement in data collection and analysis, creation of categories from the data, the development of middle range theories to explain processes and behavior, and theoretical sampling to review and refine categories (Bryant & Charmaz, 2010). While short excerpts are included here as illustration, it is most edifying for the reader to view uploaders' stories directly because "storytelling reveals meaning without committing the error of defining it" (Arendt, 1968, p. 105). In this study, the method of analysis necessarily defines the story. Only videos that contain representations of seizures or discuss epilepsy directly are included in the study, and while there are many postings concerning seizures in pets, this study is confined to humans. Videos, narratives, and ensuing commentaries including uploader comments, top comments and all comments were included in the data set.

Thirty-five percent of the videos in the data set are posted by medical or advocacy organization and 65 % are personal. Of the postings that feature people with epilepsy, 48% are female, 44% are male and 8% include males and females; the great majority (67%), are Caucasian; 48% are infants or young children, 8%, adolescents, 40%, adults and a very small percent featured subjects of multiple ages. Based on our observations, there are no postings of children between five or six years of age and adolescence and almost all of the adults appear to be 35 or younger.

Obviously, the videos of infants and children are posted by parents. The numbers of views of postings range from under 500 (6), to over a million (2) with the great majority being under 100,000. Sixty two percent of the videos are self narrated or narrated by someone related to the person with epilepsy, 28% by medical professionals or advocates, and a small percentage by others. Most examples include text in addition to voice, and all of the personal videos are followed by some commentary. The great majority of personal uploads are made at home and the medical and advocacy uploads are generally in offices or meeting rooms.

### Analysis

Based on the data, we were able to draw seven generalizations about the characteristics of the posters and their motivations, uploads and commentaries, and the differences between uploads by organizations and individuals. These generalizations support our contention that uploads can be interpreted as representing people's and organizations assertion of their "right to appear." Posting is an overall example of the right to appear through action and speech.

1. Even the simplest of these postings are illustrations of someone having a seizure, with no accompanying narrative. Still, they allow for the subject to be seen and disclose material that society generally chooses to hide from public view. Examples are: *Lewis having a seizure*. Posted 5/19/08, cited 6/6/10). *Absence Seizure. My six year old daughter having an absence seizure* (5/20/08) and *Chase 16-month-old myoclonic*. (12/06/08). These are posting of infants and toddlers; all are made in the home by a parent. Other postings include oral or written descriptions that describe what is happening in the video, such as the following:

*Myoclonic? Apparently . . .* (11/6/08). "Charlie started doing more jerking and usually in response to stimuli. We had an EEG scheduled to determine if it was seizures but before that they advanced into full-blown seizures that were unmistakable. We still have the EEG scheduled. I guess we'll find out if she's having any we don't recognize."  
*Abby's Seizure*. (Posted 5/11/09, viewed 7/2/10). "Let's take video of Abby.. We gotta see what's going on, okay mommy?" "We were getting ready to go to daycare," "She's

kind of just straining, there it goes right there" "just thought I'd take a video so we can show it to Dr. Z when we go in on Wednesday." "This has been going on for about two minutes already" "So we can show the doctor what's going on with you now."

2. Postings by organizations differ from those by individuals. Organizations are communal domains in which individual performance is structured to fit the goals and viewpoints of the larger entity (Arendt & Kohn, 2005). Thus, organizations' views of how the condition should be presented affect their choices regarding who should appear and the messages that should be presented. Some videos made by medical professionals and advocacy groups suggest that the lives of people with epilepsy are not compromised by the condition, while others say that epilepsy is difficult to manage and sometimes deadly. Normalizing examples suggest that most people with epilepsy have no related conditions and live like those who have no chronic illness. Examples of normalizing statements are: "Epilepsy is perfectly compatible with a normal happy life" (Health Guru, 11/19/07), "I'm just like you" (Epilepsy Foundation, 1/26/07) and "The Epilepsy Advocates are people living with epilepsy and caregivers who face the challenges of epilepsy every day and have found a way to overcome these challenges through education, epilepsy treatment, and community" (Epilepsy Advocate, 2011). A very different message can be seen in the CURE (Citizens United for Research in Epilepsy) 2011 Annual Video. That video "shares the stories of other family members impacted by this devastating disease – siblings and children of those with epilepsy and seizures" who speak of the extraordinarily difficult problems that they and their ill relatives have endured (CURE, 2011).

Epilepsy organizations and concerned individuals seem to be moving towards acknowledging the range of epilepsy presentations. As Brien Smith, a neurologist with epilepsy, said in a recent article in the *New York Times*,

There are Supreme Court justices who have had a couple of seizures and function normally. There are adults who have had significant head trauma, strokes or brain



tumors. And there are individuals for whom epilepsy is catastrophic – children who all of a sudden find themselves going down a path where there is a strong likelihood they will never have a normal life. (Chen, 6/28/11).

In spring, 2010, five epilepsy organizations, the American Epilepsy Society, Epilepsy Foundation, Epilepsy Therapy and Development Project, International League Against Epilepsy and Citizens United for Research in Epilepsy gathered to create a vision statement the beginning of which says,

Epilepsy hijacks the lives of one in 100 Americans of all ages. It is an indiscriminate, unpredictable, misunderstood group of ever-changing diseases that manifests itself in seizures, brain damage, and cognitive and psychiatric disabilities” (Resnick 2010).

The Epilepsy Foundation has drafted a bill called the RAISE Act (Raising Awareness and Insight into Seizures and Epilepsy) whose introduction it continues to support. The Act would create a campaign to increase awareness and understanding of epilepsy in important social institutions (Gauriemma, 2011). House Resolution 298, introduced by three members from different states, is a step towards the introduction of the Act. The “Talk About It” and “Get Seizure Smart” campaign being waged by the Epilepsy Foundation of America addresses this quandary as well. For example, NBC’s *Heroes* star, Greg Grunberg, whose son has epilepsy, has made a video called Talk About It (Grunberg, 2011), and the Epilepsy Foundation of America has an eCommunications page on its website on which anyone who is affected by epilepsy or seizure disorders can communicate (Epilepsy Foundation, 2012). There are also YouTube postings such as *Don’t Freak Out About Epilepsy* (12/1/06) that are professionally constructed but wish to appear homemade and offer no information about auspices.

In all, the great majority of the uploads are personal videos posted by those who have been diagnosed with epilepsy, their friends and relatives or occasionally (1% of the data set) by those who pretend to have a seizure in order to entertain. Placing the personal into the public domain

may be a redefinition of public and private boundaries with which many may be uncomfortable, but it is purposeful. This kind of placement is yet another demonstration of how cultural understanding of public and private domains are social and political constructs (for an exploration of Arendt's thoughts on the subjects, see Benhabib, 1996). Personal narratives bring new or previously hidden perspectives to the fore. Postings of infants and toddlers having seizures are by parents as reports for their children's physicians, to others or simply to share their experience. Sometimes, they include voiceovers, text and music. It is as if those posting were responding to a request to tell this vast, unseen audience about themselves in the most introspective, thoughtful, respectfully intimate way possible using words, artistry and music. These never feel like a sideshow. Many are self-posted to talk about wishes for an agreeable life, to seek support or find community.

3. According to their stated purposes, almost all uploads want to educate the viewer about the medical aspects of epilepsy and its symptoms, how it may be related to other conditions, and how it affects the individual and the family. Below are excerpts from a video narrated by Zachary's parents. Here, one sees use of names, talk of the meaning of the condition in family lives and a multi level seeking of community.

*Our Testimony, Zachary's Story* (posted 10/6/08, viewed 6/8/10). I was asked by my pastor to produce . . . our testimony for the grand opening of our church . . . It's the story of Zachary's life from birth up to now; he's 19-months old.

Renee and I had been married for about two years, when she got pregnant. About 34 weeks in, her blood pressure started acting up. . . The doctor said, "He has got to come out now." He came out 3 pounds and 7 oz; he was unable to breathe on his own and was having heart failure. . . When he was about six months old, he started having these spasm seizures. He would fly forward with his palms up above his head. . . The neurologist told us he had something called "infantile spasms" or "West Syndrome," which is a kind of infantile epilepsy. The MRI showed significant brain damage, and they diagnosed him with cerebral palsy. . . we went through a process of medication, and the seizures completely stopped. . . Having a special needs child has brought us closer as a couple, closer as a family, and has brought us closer to God. We are really amazed that God can take something that is so devastating and he can give someone purpose. And when he

gives you direction, he says “Here’s your direction, do something with this.” And it has put us in a community of people who can say that they have been there, and that there is this amazing, awesome God that can carry you through it all.

Following is some commentary that follows the upload. It is a typical of most commentary.

This is about the 3rd or 4th time i've watched this video, it amazes me everytime how positive and strong you two are, and all the faith and love you both have. Zak is a miracle, and a blessing. God has made many people special and he sure did make Zak extra special. God bless you, you guys are an inspiration to many. [sparklescuzishine](#) 7 months ago [@sparklescuzishine](#) God bless you too. Thanks for the comments. We are blessed that Zachary is able to bless, inspire and give hope to others through his story. Wishing the best for your family too! [ncharlan](#) 7 months ago my baby also cp, zach video give inspiration for me. im also need to learn much about u n wife did for zach. thnx for share this. god bless ur family [smileldya](#) 11 months ago [@smileldya](#) Thank you. Let us know what questions you may have. Send us a message through YouTube. We know it can be an overwhelming experience and journey and will help you out any way we can. [ncharlan](#) 11 months ago

4. The design aspects of each posting, the mise-en-scene, show the poster’s concern with individualizing the presentation, creating a tone and taking the production beyond words or voice. The postings of medical organizations present physicians behind a podium or desk often wearing white coats and with the emblems of the institutions strategically placed in the scene. These workplaces are where the equipment and personnel are housed and where the organization shows its authority. Personal postings of infants and children are all in the home, either in the kitchen, living room or bedroom. Postings from teens are always in the bedroom. Sometimes, pets are included in the video. Just as organizations display the trappings that indicate their authority, families choose to video in their homes for ease and comfort, and teens video in their bedrooms, their personal domains. All told, the mise-en-scene of each video enriches speech and action allowing the poster to create what the viewer will experience. In *Epilepsy isn’t always Peaches and Cream*, the young woman is filming in her bedroom with a kitten roaming on her bed behind her. She is wearing makeup and sporting a white fedora with a lace band. In *Me &*

*Epilepsy* (1/8/11, 12/16/11) the poster has chosen a plain background with the word LAUGH printed large on the wall.

5. Individuals want to be seen and named. In terms of the right to appear, people want to be identified because “action without a name, a “who” attached to it, is meaningless (Arendt, 1998, pp. 180-181).” Especially for infants and young children, names are often in the title of the video: *Yafaau’s convulsion videos* (posted 3/12/07, viewed 12/20/11), or *Simon’s seizure* (posted, 2/11/08, viewed, 12/18/11). Adolescents and young adults name themselves or their names are used by video narrators. Those leaving comments also appear by name and engage posters and other respondents.

*My Epilepsy vids2* (posted 3/6/09, viewed 12/14/11). This posting includes text that was written by Talia, the person with epilepsy, and also a voice-over that was included by the man making the video. He gently calls her, “Talia, Talia. You feeling better. You have to get a bit of sleep now. I think you are.” Following Talia’s text is inserted into the video. “Sometimes seizures occur while I am tired or already asleep. I am unaware of what is happening to me or my surroundings. Afterwards I feel dreamlike, floaty, I can be partially aroused at times. I usually fall asleep quickly, sometimes I may have more.”

Another set of examples is a series of videos still photos of a toddler named Riley that her family made over a four year period. The content shows Riley’s home and her loving family, parents, older brother and grandparents in everyday, quiet moments, family celebrations and a school or church play. The music that accompanies the video is Joe Cocker’s version of *Everybody Hurts* (2004), and Martina McBride’s *In My Daughter’s Eyes* (2003)

*Riley’s Journey with epilepsy* (Posted 4/11/08, viewed 6/6/10). Born April 2004. Everything was perfect. Then Riley suffered her first seizure at 6 months of age. The affects of epilepsy extend far beyond seizures. Developmental delays can include academic underachievement, social stigma, deficient communicative skills. The entire family is affected by epilepsy and its afflictions. Riley’s seizures have been the cause of hospitalization for up to 9 days at a time. Riley has had as many as 220 seizures in one week. Each day that passes without a cure limits Riley’s quality of life.

Following is a comment from someone who viewed the video, and following that is a response from the poster, krcr4.

I just want to say that i have a baby that has epilepsy 2 and i dont know what to do every time that she has an seisure i want to die i feel so bad please let me know how did u manage this cuz i dnt know ([kme118209](#) 1 year ago). I take it one day at a time and don't let the doctors stop trying to find a better drug combination or other ways of treating the epilepsy. I also try to really enjoy the times we aren't dealing with the seizures. Hang in there. Find a support group in your area. My support group Epilepsy Support Network of Orange County has been a life saver. Prayers for your baby([krcr4](#) 1 year ago).

6. Personal postings almost always are about describing and explaining the experience of having a seizure and living with epilepsy. The following example is from *Baby has seizures but misdiagnosed as colic or reflux* (posted 9/4/08, viewed, 11/29/11) which has had 124,111 views and 536 comments with no responses from the poster.

We took our baby to the pediatrician and a special "Colic Clinic" to determine what was wrong with him for the first 8 weeks of his life. Unfortunately, he never displayed any "episodes" while visiting doctors. So it wasn't really the fault of our doctors that he was misdiagnosed. We filmed our baby out of desperation and finally got some attention. Before this video received any comments, we had already gone to the emergency room. It was determined that he was having multiple different types of seizures all at once (no signs of "classic seizures"). After an MRI, we received the diagnosis that he has hemimegalencephaly. . . Although he didn't display this intense episode all along, it finally got to this point after 6 or 7 weeks. If your baby "jack-knifes" or rolls his eyes back, please take him/her to a neurologist or the ER. Our doctors asked all along if he turned blue, but he never did. Just because your baby doesn't turn blue, doesn't mean he's not having seizures (if he's showing these other signs). Thank you to all the concerned folks who sent us comments. We hope this video will be helpful to others in our situation.

Many posters want to engage others actively. For example, in *Nathan Bovell – having a Tonic Seizure* (posted 12/8/07, viewed 12/10/11), Nathan's mother says, "DO NOT WATCH THIS IF YOU GET EASILY DISTRESSED OR UPSET. This is for people that want to know how life with epilepsy. One comment is typical. "God bless you Nathan and Nathan's mom. He is so beautiful. I hate the helpless feeling of watching your child go through this." Commentators thank the poster saying that they are parents themselves, or health care students or teachers, and

Nathan's mother responds to many. *The downs of having epilepsy/seizures* (posted 1/12/11, viewed 12/30/11) begins, "It's Kanae here" and the line under the video reads, "Me discussing the roller coaster of living with epilepsy" Kanae did not respond to those leaving comments.

I'm basically making this video because I wanted to talk about my life with epilepsy and, you know, the struggles that I face on a day-to-day basis. Life with epilepsy for me has been really lonely because I find it running off friends and boyfriends and just people in general. . . People define me as "epilepsy." I feel so self-conscious about being an epileptic person. I feel like now I need to hide it. . . I don't need to wear my medical ID bracelet because as soon as people know, they look at you different. Deep down inside, they think you are some kind of weirdo or some kind of freak or something. It hurts me because I feel like crap. I feel about this small because people don't stop being my friends due to my being mean or a bad friend or I said something. . . Guys don't stop being my boyfriend because I cheated or something. It's only because I have epilepsy and they had to deal with a seizure now and again. And I want to express that if I could choose not to have epilepsy, I would do so. I wish that people would stop acting as if this were something I chose for myself. . . I feel that every person should be accepted for who they are, not made to feel ashamed and just want to crawl into a hole and hide from the world because they have something that they have no control over. I just wanted to talk about that because if there is anybody out there who feels like I do, I want to know them to know they are not alone and if somebody wants to talk about it, you can leave me a comment or message.

7. Most postings are positive, hopeful and try to be helpful. One example is *Epilepsy and Me* (posted 4/6/09, viewed 11/23/11), an almost 9 minute video contains embedded photos and a voiceover narration. It was made by Jen, a teen with juvenile myoclonic epilepsy in her colorful and attractive bedroom. She speaks with animation, warmth and a sense of humor. During the video, Jen inserts several short videos of her self-described "twitching" with one short insert showing her putting on eye makeup, and photos of herself in the hospital during an EEG. Like the other postings in the data set, the poster has managed the mise-en-scene, the design aspects of her production including everything that appears beyond word or voice, as much as she is able. She describes the experience of having a seizure and living with epilepsy.

Hi, I'm Jen. I'm 16 years old, I'm a sophomore in high school, and I have epilepsy. I'm not the girl from the Blair Witch Project. . . I decided to record a video about epilepsy since it affects my daily life I guess I could give a more human point of view than "Dr.

so-and-so,” and break it down normally. I couldn’t really find any other videos about what I was going through to kind of comfort me, I guess. So, this is going to be my shot at it. This is going to be a long video, because I deal with this everyday. . .I have juvenile myoclonic epilepsy, which basically means I twitch... “(TXT on the screen). On a bad day I have over 2,000 myoclonic seizures.” I have good days and bad days. . . I have been in and out of the hospital. I had a grand mal on 12/08/07. I missed a date for that. “Hey, I can’t go on a date tonight, I’m in an ambulance.” Cool. . .I take these little pills, called Keppra, twice a day, every day. Every morning, I wake up and take a pill. It’s part of my life ... I can do everything normal kids can do, I horseback ride, I swim, I eat and burp a lot..[burps for the video]. . .I’m very pro talking about epilepsy. . .A lot of people are ashamed to be epileptic or don’t want to tell people, and I understand that viewpoint. Some people don’t respond well, and the questions can get old, but if you don’t talk about it, who is going to talk about it? They will just listen to the stigma. Exorcism, people keep thinking that’s epilepsy, whatever they see on TV, like ER and other shows. . .There are two ways of looking at epilepsy, you can either laugh about it or cry about it, I do a little bit of both, but I laugh about it more because “Positivity is one of the greatest medications”. I read that on a fortune cookie somewhere, but it’s so true because if you just get in one mindset it will just take you down. . .So basically, that’s me. . . If you look at me, nothing’s wrong with me, but sometimes I have epilepsy, don’t be scared. . . This is just a little insight, now you’re educated. “Thank you for watching”.<sup>i</sup>

Jen inspired a conversation between several commentators about general symptoms and video displays; she continues to respond to comments to her posting of almost three years ago. Also, Responses to *Seizures, epilepsy, convulsions, lupus, Rachel light no diagnosis April Sun 2011* (posted 4/24/11, viewed 12/30/11) includes many comments between the poster and others. The poster talks about her frustrations when physicians were not able to find the right diagnosis. Commentators asked how she was feeling, and gave advice about emergency room visits. While the great majority of remarks are positive and supportive, some are not. One commentator responds to a video of a baby having a seizure by suggesting that the baby be put to sleep. Others are angry particularly at parents who post their children’s seizures. For example, in response to *Yafaau’s Convulsion Videos*, someone wrote: “I think this is not a good choice when publishing these videos, what do you want doing this? There's a lot of the same little boy. Who uploaded this is a bastard.” A note after *Simon’s Seizure* says, BADASS I HOPE THAT BABY FUCKEN DIES. Remarks after *Lewis Having a Seizure* say that it’s nasty to video your child

having a seizure and your child will be embarrassed, ashamed and upset about this when he is older. Wait until he gets older and finds himself on YouTube having a seizure. YouTube has methods for dealing with inappropriate responses, posters can take down their postings, and when negative comments appear, they are met with protective rejoinders from others.

The following voice over material that resembles many postings by teenagers and young adults includes parts of a 14 minute video whose plain background has the word 'LAUGH' printed in a large, elegant font. It is a demonstration of a teenager named Tazia's need for action and speech, and choosing to post material that is usually hidden. Tazia wants to educate the viewers, and tells the viewer how she is building community for herself.

*Me and Epilepsy* (Posted 1/8/11 viewed 2/9/11). My name is Tazia, and I was diagnosed with epilepsy at the age of 7, and I'm 14 now. . . Anyways, epilepsy is not a commonly talked about thing, but it is just as common as breast cancer. I think most people out there think epilepsy equals seizure, and seizure equals grand mal seizure, and that's half true and half not true. Epilepsy usually equals seizure, and seizure equals a lot of things. I've gotten six bumps on my head before from having a seizure in the bathroom, because you never know when they're going to come. You don't have a little alarm on you, it just comes whenever it feels like it. You could be the smartest person in the world, you could be Einstein, and not know when seizures are going to come, okay? . . Epilepsy can make you feel alone at times, it can make you feel sad; it can make you feel upset and angry; it can make you have major headaches. I've had to cancel on dates because I had seizures. I have had to go to the hospital for an emergency. It's not fun, it kind of sucks at times. . .Epilepsy, people don't know much about it. I go on epilepsy.com, and they have chat rooms for kids and adults who just want to talk to somebody who understands what they are going through, and they also have stuff for parents on there. . .They tell you about people being depressed, I know I've been depressed from epilepsy before, and it hasn't always been happy for me, but it hasn't always been terrible for me either. . .Ever since I started using that, I've just felt so much better, they have blogs on there you can read. . .I'm only 14, but my mom - I can see it in her eyes that she stresses about me all the time. Epilepsy is dangerous, but is not that bad. You can still be a perfectly normal teenager. You just have to do things in a different way, and take your medicine, talk to your doctor a lot and give them updates, and you'll be fine. Just remember, there is always a light at the end of the tunnel, and it's never going to be that bad. It always gets better.

## Conclusions



Posts about epilepsy on YouTube can be interpreted as expressions of an intuitive sense on the part of the posters that they have the “right to appear.” This is true for organizations with their particular points of view as well as individual posters. These posters want to educate viewers about the medical aspects of epilepsy and its symptoms, how it might be related to other conditions and how it affects the individual and the family. They do so by managing the mise-en-scene, describing and explaining the experience of having a seizure and living with epilepsy, naming posters, subjects and commentators and engaging with others through posting and presenting themselves positively.

Arendt suggests that narratives bring new perspectives to the fore and that “opinions are formed in open discussion and open debate” (Arendt, 1963a, p. 268). Those posting want the audiences to know their experiences with epilepsy, and they welcome responses. While it might seem that the level of personal posting would be uncomfortable for many people, the educational contribution is substantial. Through YouTube, people have a way to gain control not of the illness and its symptoms but of what an anonymous audience sees and understands. Overall, personal postings talk about epilepsy in ways that contribute to greater understanding and, hopefully, will allow for greater financial, emotional and social support for those who have the condition, for their friends and relatives and for researchers and educators. By contrast, medical and advocacy uploads want to educate viewers and often have the tone of marketing devices for specific organizations. They tend to reflect a conflict within the epilepsy community as to whether epilepsy should be presented as a devastating and life-threatening condition or one that is not difficult to normalize. It appears that these conflicts are beginning to be addressed.

The findings from this study raise the following question for social workers and others: “How does one incorporate these voices into one’s practice, not just with people with epilepsy but those with many kinds of chronic illnesses and conditions? Arendt (1963b, p. 250) observed: “It is in the very nature of things human that every act that has once made its appearance and has been recorded in the history of mankind stays with mankind as a potentiality long after its actuality has become a thing of the past.” Even if these postings are ephemeral and opportunities like this will change as a result of YouTube becoming a profit making entity, they have been recorded. Varying organizational experiences that are posted on YouTube provide an interesting understanding of the some of the quandaries faced by the epilepsy community, and the public postings of most private experiences can add to the education of social workers and other health care professionals through their honesty and bravery.

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